

For Confidentiality in AIDS Testing

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By Henry A. Waxman

Renewed attention is being focused on questions about AIDS testing. Who should be tested? Should it be voluntary or mandatory? Should test results be kept confidential or made public?

Although the test for the virus that causes acquired immune deficiency syndrome has been licensed for nearly two years, we don't yet know its scientific value, and its usefulness is still being debated. Nevertheless, some politicians have proposed making the tests mandatory - for example, for prostitutes, prisoners, hospital patients, marriage license applicants, pregnant women and job applicants.

But neither voluntary nor mandatory testing policies can succeed unless they guarantee that test results will be confidential and that there will not be discrimination against those who test positive. We cannot expect people to respond to medical advice if, in doing so, they risk losing their jobs, housing, insurance, children and privacy.

Moreover, misuse of testing and test results could damage the nation's ability to study and understand the AIDS epidemic. What we know about the disease we know because homosexual men and AIDS patients have volunteered to cooperate with research efforts. If misguided testing drives these people away, it could only prolong the epidemic.

We know for certain several facts about the AIDS virus test: It does not indicate who is sick or even who will become sick. The test identifies most, but not all, of those who have been exposed to the disease and who are probably infectious.

Since the disease can be transmitted only through sex or an exchange of blood, other than for blood banks the test results are useful only to the individual and to his or her sexual partners. The social utility of widespread testing is to protect those sexual partners who are not protecting themselves. Proposals to find previous sexual partners are dependent not just on the memory of the individual but also on his or her willingness to name names.

A confusing array of testing policies has already been proposed. The Public Health Service encourages anyone who thinks they have been exposed to the AIDS virus to be tested. The agency has also supported confidentiality of test results and has issued statements opposing discrimination against people who test positive as well as people with AIDS. The Justice Department has determined, however, that if the test is positive, any subsequent discrimination is legal and is not the Government's concern.

The certain result of this mixed Federal policy is that all voluntary testing programs will fail. The only volunteers for a test, which might cost an individual everything, would be those who have no reason to fear the outcome and those who are already sick and may need the test results to qualify for the little health care that is now available.

Those whom public health officials most want to test - those who might have been exposed and those who might be infectious - will stay away.

Without confidentiality and anti-discrimination protections, the mandatory testing programs are also sure to fail. Black market blood tests, forged identification cards, bribery, safe houses and fugitives - all could result from such tyrannical tactics that are in effect a house-to-house search.

In practical terms, the cost of a vast mandatory testing program would be prohibitive. Furthermore, a de facto quarantine of those who tested positive and subsequently lost their jobs, insurance or housing would produce a permanent class of people who could not provide for themselves.

If policies of confidentiality and nondiscrimination were in place, there would be reason to be more optimistic. If Americans believed they would be treated as citizens with rights, they would respond as citizens with responsibilities. If test results were treated as health information and not licenses for jobs and housing, those in danger might volunteer.

We should protect the public health by protecting confidentiality and fair treatment. If the Justice Department does not reverse its position, then Congress should pass legislation that protects against misuse and assures confidentiality of test results.